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Articles

Youth Voices as Change Agents: Moving Beyond the Medical Model in School-Based Health Center Practice

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ABSTRACT: This article describes a 34-week pilot project aimed at improving health care service delivery for adolescents by offering youth a distinct role as advisory board members who help shape policy, provide feedback, guidance, and direction to a school-based health center (SBHC) program in Boston. Freshmen were recruited to participate in a Youth Advisory Board Project that included weekly afterschool meetings. Adult supervision was provided by SBHC staff that included 2 clinical social workers and 1 youth empowerment specialist. Through this effort, students were (1) trained in nonprofit board development and governance structures; (2) urged to identify gaps in services; (3) taught to select, prioritize, and implement action projects; and (4) offered clinical support around personal issues. Students brought a wealth of life experiences, knowledge of teen attitudes, information regarding trends in risk-taking behaviors, and feedback about experiences in the SBHC. In addition, their increased awareness of the SBHC service elements led to identification of obstacles to youth participation in care, feedback regarding positive and negative health care experiences within the SBHC, as well as with external health care providers, and ideas about unrecognized needs leading to gaps in services. This experience demonstrated that young health care consumers, with support, can focus their attention and begin to utilize analytical thinking skills to shape health outcomes and inform service delivery. (J Sch Health. 2005;75(7):239-242)

Over the past decade, there has been considerable concern expressed about the health status of adolescents. After early infancy, adolescence is the period of greatest general health vulnerability until one becomes elderly. It is estimated that 1 in 5 adolescents suffers from at least 1 serious medical problem. In addition, 20% to 50% of youth experience less severe health concerns that are not life threatening but can cause distress and impair ability to function. Most of this decline in health status can be attributed to poor health maintenance and risk-aking behavior. In addition, adolescents use health care services at a rate lower than any other age group.

Numerous research and advocacy groups have emerged to develop a clearer understanding of risks and needs of the adolescent population and to identify strategies to improve health outcomes for youth. Traditionally, these researchers, advocates, and policymakers have relied on data obtained by examining the prevalence of high-risk behaviors, morbidity, and mortality; health service utilization patterns; and feedback from clinicians and parents. While these efforts played a critical role in developing recommendations for improving adolescent health care, they lacked a vital perspective: the adolescent's. A few researchers, however, believe that adults cannot fully understand the problems confronting youth or comprehend the behavioral risks and benefits perceived by youth. Therefore, the search

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for effective solutions requires collaboration between adolescents and adults.⁷

School-based health centers (SBHCs) were established to reach adolescents by bringing health care directly to them. Traditionally, SBHC services are designed for youth. SBHCs aim to accomplish their goals by offering easy accessibility in a setting where youth spend a majority of their time, providing a range of services that caters to the unique needs of adolescents, and employing practitioners with specialized training in adolescent health care. Despite their efforts to be adolescent friendly, SBHCs tend to be overseen by hospitals or community health centers and they still work within the traditional medical model. The traditional medical model does not tend to elicit direct input from patients when making decisions.

The traditional medical model approach to care places all decision making on the medical provider and expects the patient to comply with a given prescribed plan.8 This model, however, may not be the most effective approach when working with adolescents and may actually discourage adolescents from utilizing health services—the primary goal of SBHC programs. Adolescents often want to exercise their independence and resist being told what to do or how to act. A patient empowerment approach9 has been suggested for use in treating certain chronic illnesses and may be more efficacious when working with an adolescent population. This model stresses that patients themselves are ultimately responsible for their own care and as such need to develop a collaborative relationship with their health care providers. Proponents of this approach stress that giving patients a voice in their care ultimately improves health outcomes as well as patient-provider relationships.

The patient empowerment model also may have efficacy when extended beyond the medical examination room and into the boardroom. Research has shown that youth involvement can lead to positive outcomes for organizations, communities, and youth themselves.¹⁰ In a study that sought to elicit youth input regarding factors affecting health care utilization, researchers discovered that teenagers felt important, respected, and valued when asked to help adult providers better meet the needs and expectations of youth.⁷ Armed with the positive research findings in much of the youth involvement literature, and faced with a need to address several programmatic challenges, the administration and staff of a Boston SBHC program decided to engage adolescents more significantly in the planning, implementation, and evaluation of services.

PILOT PROJECT METHODS

Background

The Boston SBHC where the intervention occurred had been in existence for more than 10 years. It was overseen by a large teaching hospital. After the first year of SBHC operation, an advisory board was assembled to assess progress and identify gaps in services. The advisory board met quarterly and primarily comprised adults including clinicians, school personnel, parents, and community/business leaders. On occasion, 1 or 2 students would be invited to join the group, but they rarely assumed an active role. As a result, the board had limited efficacy because it lacked a consumer perspective.

The primary goal of the development of the SBHC Youth Advisory Board Project (YABP) was to elicit and use feedback from youth consumers of the SBHC program to inform program changes. It quickly became evident that these tasks could not be accomplished in the traditional advisory board format that was dominated by adults. True youth involvement could only be achieved in a group where youth could process ideas with other youth and feel that their input was valued. Furthermore, listening to students and incorporating their ideas into clinic programs and policies could help transform the SBHC from functioning under a strictly medical model to a patient empowerment one. Establishing a structure that facilitated this necessitated recruiting students and identifying appropriate adult supervision.

The inception of the YABP coincided with significant changes in the SBHC funder's governance regulations and structural adjustments to the mission of the host school. In 2002, the funder mandated that SBHCs have governance boards that met monthly and predominantly comprised consumers. In addition, the school shifted from a traditional curriculum to one that emphasized the study of leadership development and the complex process of social change and community problem solving. Consequently, the YABP endeavored to augment the existing advisory board structure, complement the school's mission, and promote the development of youth leadership skills within the health care arena. Thus, the purpose of the YABP was to identify and train students as board members who could then generate ideas, implement projects, and collaborate with adult members. This article highlights the YABP over 1 academic year (34 weeks).

Recruitment

Recruitment for the YABP began in fall 2002. A decision was made to target freshmen (N = 125) because they

could serve as change agents for the entire period they were enrolled in school. A weekly afterschool meeting was selected as the venue in which to work with students. The school had recently initiated a mandatory afterschool program. As a result, the YABP linked with the afterschool program, which facilitated recruitment. Twelve ninth-grade female students ultimately joined the YABP. Participants ranged in age from 13 to 15 years. Between 8 and 10 students typically attended meetings. Racial/ethnic distributions of the group closely mirrored that of the school and were as follows: black (4), white (1), Latino (3), Asian (1), and Other (1). Attendance was taken at all meetings. In addition, minutes pertaining to meeting highlights were regularly maintained.

Staffing

SBHC staff that included 2 social workers and 1 youth empowerment specialist oversaw the YABP. Social workers were selected for their extensive clinical experience with youth, firsthand knowledge of medical and psychosocial issues impacting the student population, experience in facilitating a group process, and a desire for continuous quality improvement. What these particular clinicians lacked, however, was direct experience with youth organizing and social change. The youth empowerment specialist brought knowledge of youth-adult partnerships within a board setting.

Program Format

Curriculum materials on board development and youth-adult partnerships were obtained from Youth-on-Board, an organization that prepares youth to be community leaders and decision makers. During the first month of the YABP, adult staff used these resources to provide students with introductory knowledge about advisory boards and governance structures. Additionally, the adult staff sought input on SBHC concerns pertaining to adolescent health issues. This feedback was secured through structured agenda setting, prioritizing of issues to be addressed, and a thoughtful review of both current services and the SBHC model of service delivery.

Once initial training was complete, weekly youth advisory board meetings continued. However, the meeting format was expanded to include a monthly full board meeting including adults and youth. In addition, the group decided to dedicate time to identifying, prioritizing, and implementing projects, which enabled them to put their thoughts into action and see an issue through to completion. One particular action project selected by the students focused on a 3-month fund-raising effort culminating in participation in a fund-raising walk for the health and hygiene needs of homeless students.

Another key feature of the YABP was dedicated time to discussing academic, personal, and social concerns the youth faced. By acknowledging and supporting the students through challenges, they remained engaged in the work. In addition, supporting youth through these changes and issues, within the board structure, provided a message to the youth that their needs were valued. This format maximized the youth contribution and utilized the strengths of the staff involved. Table I provides a timeline and workplan for the YABP.

RESULTS

Students brought a wealth of life experience, knowledge of teen attitudes, information regarding trends in risk-taking behaviors, and feedback about experiences in the SBHC. Additionally, their increased awareness of the SBHC service elements led to identification of obstacles to youth participation in care, feedback regarding positive

and negative health care experiences within the SBHC as well as with external health care providers, and ideas about unrecognized needs leading to gaps in services.

Students in the YABP identified several key SBHC service gaps that include (1) limited outreach and service delivery to male students; (2) lack of clinical staff teaching to patients on developing health communication skills; and (3) limited

Table 1 YABP Workplan and Time Frame

Time Frame	Elements of Workplan Adapted From Youth-on-Board Training Materials	
	Action Component	Support Component
Throughout curriculum	Why is a youth voice important?	How do societal pressures affect young people's lives?
	Putting dreams into action	How can you be an effective listener and speaker?
	Developing goals	How can you learn to practice peer
	Why should youth be involved in decision making?	support skills?
	How do you move beyond barriers?	
Months 1-2	Project development	Brainstorm and decide on format for regular support meetings
	Recruit, train, and mentor young leaders	Brainstorm topics for the next 10 meetings (ongoing development)
	Discover the importance of strong	How does one's life story connect
	youth-adult relationship change	to the work?
	Hear about other successful youth involvement efforts	How is oppression present in your life?
	Discuss how do you get stronger and feel like you can speak up?	How can you deal with peer pressure and violence in school?
	What is a Board?	How can young people gain self-confidence?
	What work can we do that complies with mission of organization?	How can young people resolve conflicts? How can one keep close relationships across race lines and within your own race?
		How do you gain knowledge about people from different cultures?
		Through the process of listening and sharing ideas, people can appreciate each other's work, learn from each other's struggles and successes, and receive encouragement and reliable information about their work, their
		lives, and accomplishing their goals.
Months 2-4	Project selection Assist in the evaluation of ideas and	Decide on facilitators for meetings (preferably 1 young person and 1 adult paired)
Months 4-6	project selection Develop tasks and responsibilities chart	Meet with facilitators separately to practice format for regular support meetings (ongoing)
Months 7-11	Work through project implementation with youth using tasks and responsibilities chart as guide	Continue regular support meetings (ongoing)
	Conduct ongoing workshops as areas for skill development are identified	After every 10 meetings, evaluate the topic, facilitators, and format to make and plan for the next 10 meetings and dates
Month 12	Assist youth and the organization with an evaluation of project success as well as identify future steps for the project and community	

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outreach and education materials to reflect the continuum of care from crisis intervention through ongoing treatment.

Male Student Outreach

Members of the YABP suggested that prevention efforts that address issues such as adolescent pregnancy, dating violence, and healthy relationships can only achieve limited success without the involvement of male adolescents. Therefore, they suggested that outreach strategies to male students be expanded beyond information on required physicals for team sports and information about sports-related issues including nutrition and injury prevention.

Health Communication

Members of the YABP felt that health education provided by clinicians needed to be broader and include health communication skills. They expressed a need to learn how to communicate with family, friends, and romantic partners about their feelings, health risks, and health promotion.

Enhanced Crisis Follow-up Services

Members of the YABP demonstrated an awareness of SBHC crisis intervention services but questioned the availability of follow-up offerings. Many stated that crises will reoccur if improvements in health or emotional well-being are not maintained. Consequently, students expressed a need for the SBHC to place more emphasis on continuing to work with students after resolution of a crisis.

DISCUSSION

The overall strengths of the YABP included engaging youth in meaningful dialogue about their health care and school programs while also supporting their development. For the SBHC program, utilizing feedback from students to understand service gaps and patient needs facilitated achieving the goals of the program more effectively than the traditional medical model approach. This experience demonstrated that even adolescent health care consumers, with support, could focus their attention and begin to utilize analytical thinking skills to shape the outcome and inform service delivery. While this endeavor had a sample size that was too small to help draw any statistically significant, generalizable conclusions, it served as a vital pilot project and case study that can inform policy, research, and clinical practice. The next steps will be to replicate this project in other SBHCs in Massachusetts and longitudinally monitor and document its impact. Efforts are under way to implement this process.

Health care is rapidly changing in response to technology, demographics, and economics. As a result of these changes, consumers may be overlooked. Nevertheless, it is vital for providers to attempt to not lose sight of the unique needs of their adolescent patients while maintaining accountability to funding sources and managed care organizations.

Lessons learned from this project are applicable to other health care programs serving adolescents, as well as other programs attempting to incorporate youth consumers into their program planning and policy development work. The lessons learned relate to program structure, the role of adult group leaders, involving youth in the needs identification task of the organization, and providing an environment conducive to information sharing and meaningful feedback.

Adolescence is a time of experimentation when children begin to make independent choices about their health. Their experience with the health system at this stage in life can impact future patterns of health-seeking behavior as well as their general health as youth and later as adults.¹¹ It is, therefore, critical to listen to what adolescents have to say and to engage them in helping to determine how best to design and deliver health services to improve overall wellbeing. Accomplishing these goals meets the needs of adolescent patients while also acknowledging the realities of the health care environment. Patients today, and in the future, need to effectively advocate for their unique needs, partner with their providers, and shape program and policy decisions.

The YABP was borne out of necessity but proved to be an invaluable learning experience for school administrators, SBHC staff, and students. Prior to this effort, the SBHC relied on external sources of feedback such as patient utilization data, anecdotal clinician feedback, and large-scale community survey data. Hence, a critical data source necessary for meeting the health needs of the school population was conspicuously missing.

Developmentally, it can be anticipated that adolescents will challenge existing norms, share information and experiences with peers, and move away from engaging in dialogue with adults. The medical model represents much of what adolescents strive to rebel against. A patient empowerment model seeks to capitalize on their strengths and capacities for change. The YABP sought to empower student consumers to shape programs and policies. The success of this effort fosters a shift to the patient empowerment model within health care encounters.

References

- 1. Burt MR. Why Should We Invest in Adolescents? Washington, DC: Urban Institute; 1998.
- 2. Office of Technology Assessment. *Adolescent Health Volume I: Summary and Policy Options.* Washington, DC: US Congress; 1991.
- 3. American Academy of Pediatrics. Managed Care, School Health and Public Policy: Strategies for Managed Care: An Update from the Committee on Child Health Financing. Elk Grove Village, Ill: American Academy of Pediatrics; 1998.
- 4. Kirby D, Barth RP, Leland N, Fetro JV. Reducing the risk: impact of a new curriculum on sexual risk-taking. *Fam Plann Perspect*. 1991;23(6):253-263.
- 5. Klein J. Adolescents, the health care delivery system, and health care reform. In: Irwin C, Brindis C, Holt K, and Langlykke K. eds. *Health Care Reform: Opportunities for Improving Adolescent Health.* Arlington, Va: National Center for Education for Maternal and Child Health; 1994:17-28.
- 6. Brindis C, Irwin C, Ozer E, et al. Improving Adolescent Health, an Analysis and Synthesis of Health Policy Recommendations, Report Summary. San Francisco, Calif: University of California, San Francisco, National Adolescent Health Information: 1997.
- 7. Ginsburg KR, Menapace AS, Slap GB. Factors affecting the decision to seek health care: the voice of adolescents. *Pediatrics*. 1997; 100(6):922-930.
- 8. Anderson RM. Patient empowerment and the traditional medical model. A case of irreconcilable differences? *Diabetes Care*. 1995;18(3): 412-415.
- 9. Neinstein LS. The treatment of adolescents with a chronic illness: physicians must go beyond the medical model. *West J Med.* 2001; 175(5):293-295.
- 10. Lerner RM, Lerner JV, Almerigi J, et al. Positive youth development, community contributions, and participation in community youth development programs: findings from the first wave of the 4-H Study of positive youth development. *J Early Adolesc*. 2005;25:17-71.
- 11. Klein JD, Slap GB, Elster AB, et al. Access to health care for adolescents: a position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1992;13(2):162-170.